IACC Strategic Plan ASD Research Budget Recommendation

Lost Potential Due to Autism

Autism is a lifelong condition:

- When accounting for direct cost (what is spent) and indirect cost (what is lost, including individual and parental productivity costs), the lifetime cost for an individual with autism has been estimated to be $2.4 million when autism involves intellectual disability, and $1.4 million when it does not.[1] Another study estimated that the additional costs of healthcare, education, therapy, services, and caregiver time associated with caring for a child with ASD aged 3 to 17 years is about $17,000 per year. [2]

- The yearly cost of autism to the United States (including medical, nonmedical, economic, and lifetime costs, etc.) has been estimated at $236 billion.[1] Another study has suggested that in 2015 the combined medical, non-medical, and lost productivity costs were in the range of $162-$367 billion, or 0.89-2.0% of the U.S. gross domestic product.[3] (According to IACC data, total autism research funding in 2015 came to $343 million: 0.09-0.21% of the estimated total yearly cost of autism.)

- Four of every ten youth with autism do not transition into a job in the first years after high school. Those who got jobs tended to work part-time in low-wage jobs.[4]

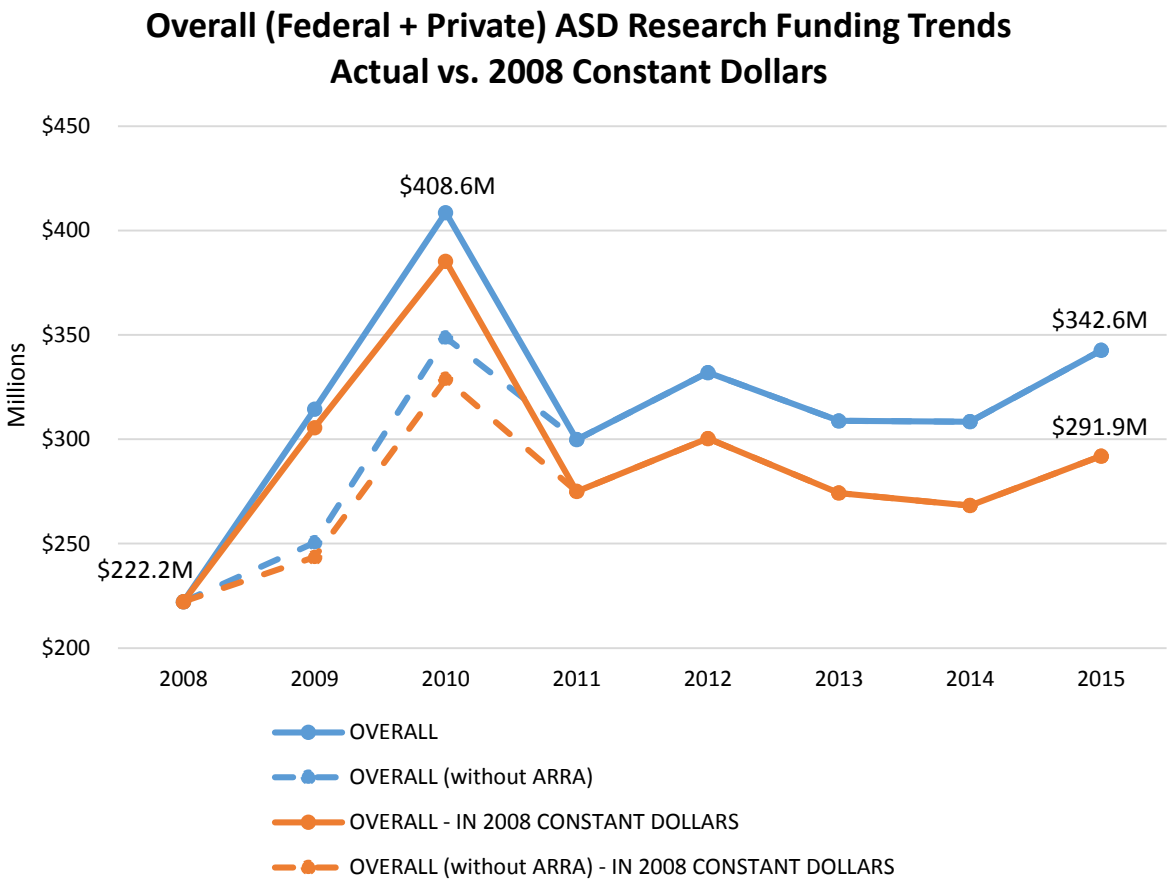
- Research to better understand the nature of ASD and the needs of children, adolescents and adults on the autism spectrum is important to help build the evidence base for efficacious and cost-effective strategies to address the complex challenges associated with ASD.

- Studies suggest that the costs of research and services that enable delivery of effective early intensive behavioral interventions in childhood can result in cost savings over the lifespan by reducing the need for costly long-term care and support.[5,6] This suggests that investment in research to improve early detection and intervention could reduce long-term service costs.

- It is likely that more investment in research to improve adolescent and adult services and supports would improve the economic productivity of individuals over their entire lifetime, while also improving their sense of purpose and quality of life.[7]

[1] *Buescher et al 2014*
[2] *Lavelle et al 2014*
[3] *Leigh et al 2015*
[4] *Roux et al 2015*
[5] *Peters-Scheffer et al 2015*
[6] *Penner et al 2015*
[7] *Järbrink 2007*

Autism Research Funding Trends



- Combined federal and private autism research funding was 54% higher in 2015 compared to 2008, an annual growth rate of 7.7%.
- When adjusted for inflation by using constant 2008 dollars, the growth in the combined federal and private autism research budget from 2008 to 2015 was 31%, an annual growth rate of 4.5%.
- The highest annual percentage increase was 41% between 2008 and 2009 (including ARRA funding).
- The highest combined budget was $408.6 million in 2010 (including ARRA funding).

Inflation rate source:
https://officeofbudget.od.nih.gov/pdfs/FY18/BRDPI%20Table%20FY%201950%20to%202022_Jan%202017.pdf

Priority Areas for New or Enhanced Research and Services Activities Reflected in 2016-17 IACC Strategic Plan Objectives

Q1 *Strengthen the evidence base for benefits of screening; reduce disparities; improve tools, access, and service delivery models*

Q2 *Advance research on development and neurobiology of autism; understand biology of co-occurring conditions; undertake longitudinal studies that cover the full lifespan*

Q3 *Continue to identify genetic risk and resilience factors; advance research on environmental risk and resilience factors; understand how genetic and environmental factors interact*

Q4 *Develop medical and pharmacological interventions; improve psychosocial and naturalistic interventions; advance technological interventions*

Q5 *Scale up evidence based interventions; reduce disparities in access and outcomes; improve service models*

Q6 *Develop and coordinate transition services; reduce comorbid conditions and premature mortality; promote acceptance, accommodation, inclusion, independence, and integration*

Q7 *Encourage tissue donation, data standardization, and data sharing; train researchers and service providers; expand surveillance to cover adults and comorbid conditions*

Cross-cutting *Expand research to understand autism in girls to ensure we are meeting the needs of this population.*

Potential Rationales for Overall Budget Recommendation

Propose an overall (federal + private) ASD research budget, with a justification, considering historical funding trends.

- Option 1: Maintain a Steady Rate of Growth in Research Budget

  Extrapolate annual rate of growth to 2020 or another target year in the future

- Option 2: Recoup Dollars Lost to Inflation Since 2008

  Adjust for the loss of purchasing power due to inflation

- Option 3: Return to the Historical High of 2010

  Identify a target date/timeframe for returning to the 2010 peak funding level

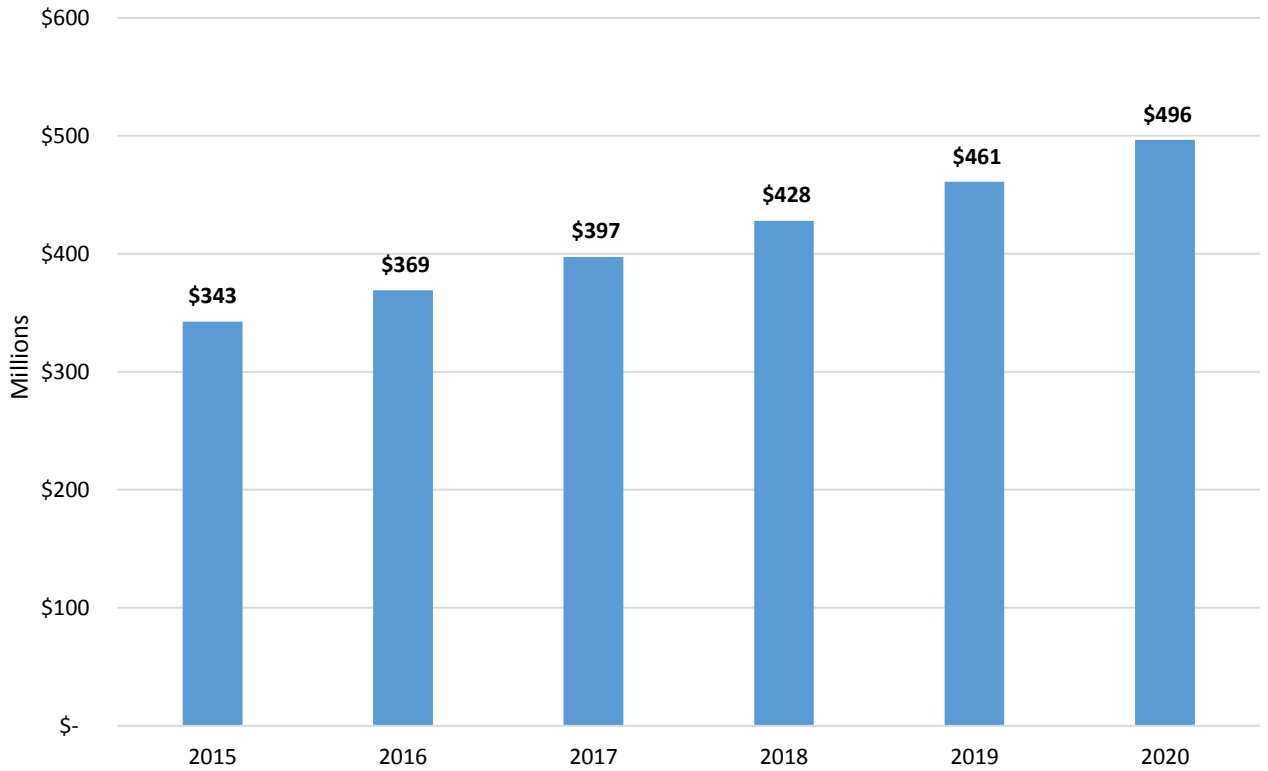
- Option 4: Significantly Grow the Autism Research Budget

  Identify a target date/timeframe for doubling the 2015 overall budget level

Option 1: Maintain a Steady Rate of Growth in Research Budget

- Extrapolate annual rate of growth to 2020 or another target year in the future

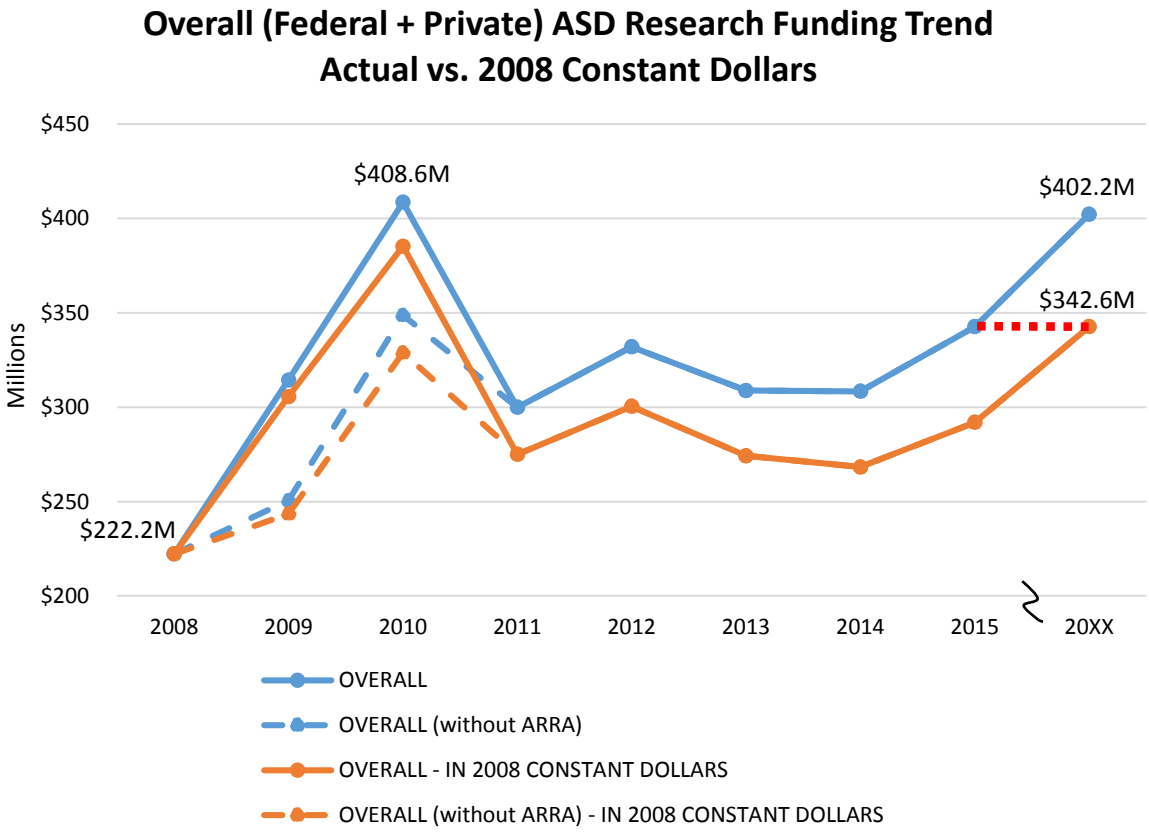
Projected Overall (Federal + Private) Autism Research Budget Levels Based on Continued 7.7% Annual Growth Rate Until 2020



All funding levels are in actual dollars and do not account for future inflation

Option 2: Recoup Dollars Lost to Inflation Since 2008

- Adjust for the loss of purchasing power due to inflation



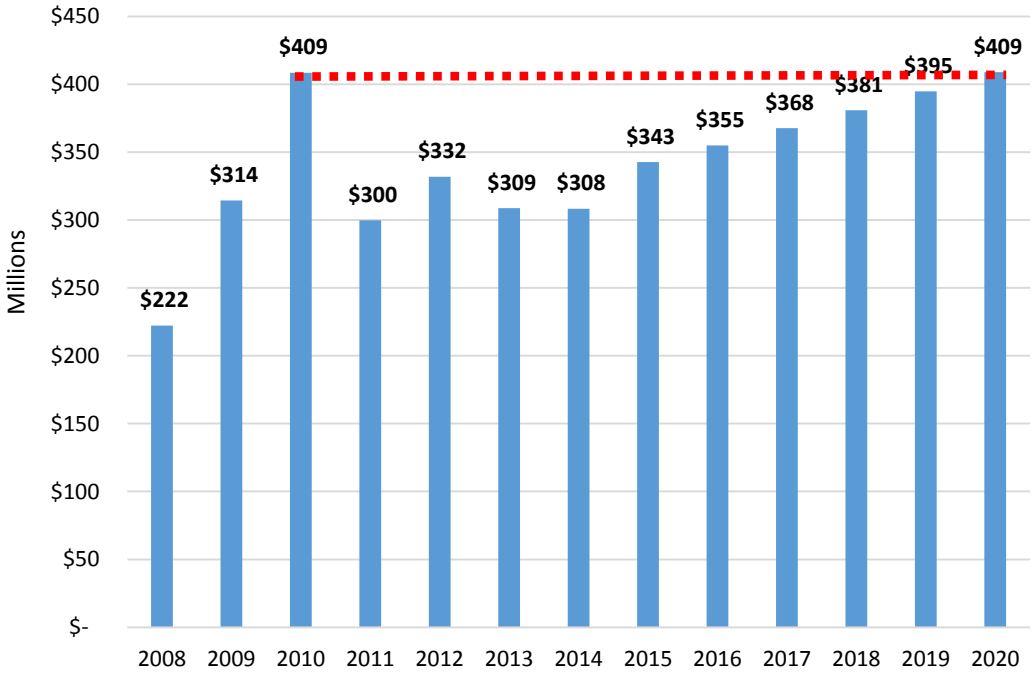
- To negate the loss of purchasing power at the 2015 funding level, a funding level of about $402 million would be equivalent to $343 million in 2008 constant dollars.

Inflation rate source: https://officeofbudget.od.nih.gov/pdfs/FY18/BRDPI%20Table%20FY%201950%20to%202022_Jan%202017.pdf

Option 3: Return to the Historical High of 2010

- Identify a target date/timeframe for returning to the 2010 peak funding level

Returning Overall (Federal + Private) Autism Research Budget to 2010 level by 2020 With Increase of 3.6% Per Year Starting in 2016



All funding levels are in actual dollars and do not account for future inflation

Science Advances Enabled by ARRA Investment

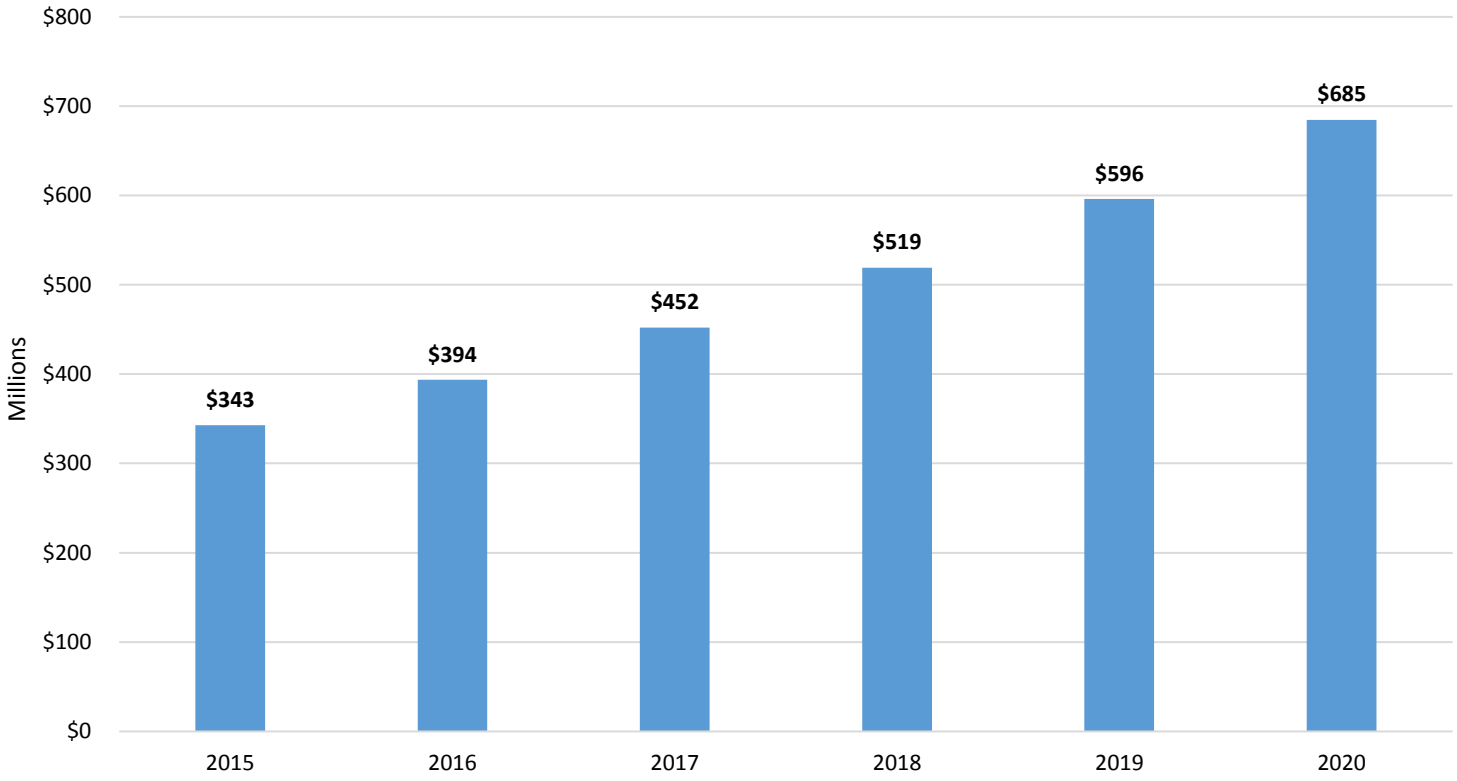
In 2009 and 2010, ARRA funds were used to quickly support new studies on development and testing of diagnostic screening tools for different populations; assessing risk from prenatal or early life exposures; initiating clinical trials to test early interventions; and adapting existing, effective pediatric treatments for older children, teens, and adults with ASD. Some study outcomes included:

- Brain imaging technology to distinguish between individuals with ASD and those serving as controls.
- An accurate method to assess the risk of ASD in infancy through the analysis of older affected siblings as predictors of ASD recurrence.
- The JobTIPS website to provide young people with ASD and their families with helpful tips and information on developing job skills.

Option 4: Significantly Grow the Autism Research Budget

- Identify a target date/timeframe for doubling the 2015 overall budget level

Doubling of 2015 Overall (Federal + Private) Autism Research Budget by 2020
With Increase of 14.85% Per Year



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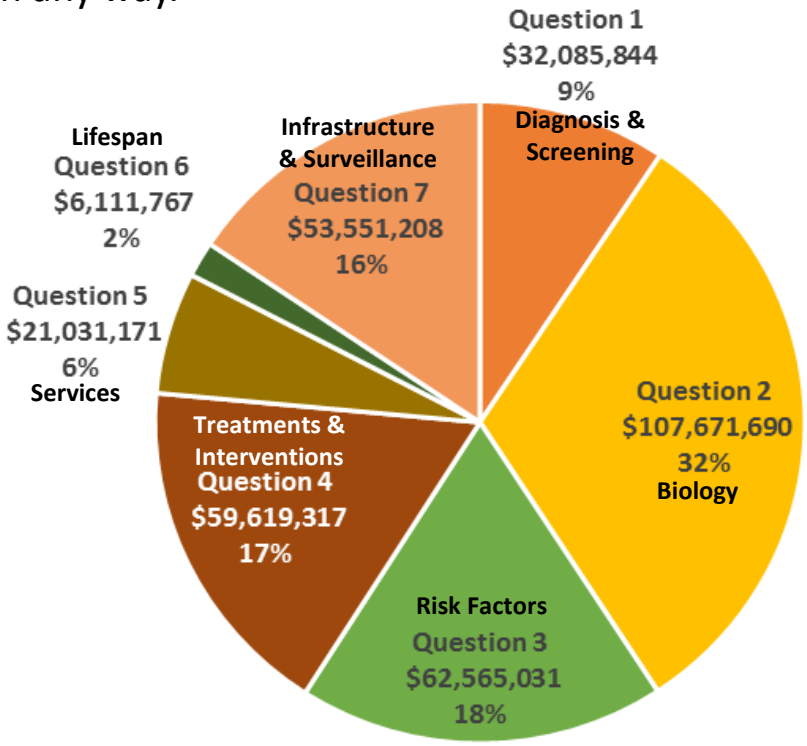
Budget Recommendation Discussion

- ***Which of the options or methods does the IACC want to use to develop the budget recommendation?***

- ***To what target date and/or timeline does the IACC want to apply the budget recommendation?***

Considering Portfolio Balance

- Using the 2015 pie chart of funding percentages by Question area as a guide, determine whether the percentages of funding for each Question area should be rebalanced in any way.



- Is this the appropriate balance of funding across SP questions? If not, what should it be? Should any additional funds that become available be distributed across the questions in order to shift the balance?
- In 5 years, what should the distribution among Question areas look like?

2008-2015 ASD Research Funding by Strategic Plan Question